Original Contribution

Use of the Word "Cure" in Oncology

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Abstract

Purpose: Use of the word "cure" in cancer care reflects a balance of physician and patient optimism, realism, medico-legal concerns, and even superstition. This study surveyed a group of oncology specialists regarding the frequency and determinants of using the word cure.

Methods: Oncology clinicians at the Dana-Farber Cancer Institute (n=180) were invited to complete a survey regarding the word cure in cancer care. Participants completed a 19-question survey regarding how commonly their patients are cured, how often they use the word cure in their practice, and details about its use. Three case scenarios were presented to elicit participants' views.

Results: Of the 117 participants (65%) who provided responses, 81% were hesitant to tell a patient that they are

cured, and 63% would never tell a patient that they are cured. Only 7% felt that greater than 75% of their patients are, or will be, cured. The participating clinicians reported that only 34% of patients ask if they are cured. For 20-year survivors of testicular cancer, large-cell lymphoma, and estrogen receptor–positive breast cancer, 84%, 76%, and 48% of clinicians, respectively, believed that the patients were cured, and 35%, 43%, and 56% recommended annual oncology follow-up of the patients. Twenty-three percent of oncology clinicians believed that patients should never be discharged from the cancer center.

Conclusion: Oncology clinicians report that patients are hesitant to ask whether they are cured, and the clinicians are hesitant to tell patients they are cured. Annual oncology follow-up was frequently endorsed, even after 20 years in remission.

Introduction

Fitzhugh Mullan, MD, a pediatrician and cancer survivor, published a sentinel article in 1986, "Seasons of Survival," describing his journey through what he described as acute, extended, and then permanent survivorship.1 Mullan and the newly formed National Coalition for Cancer Survivorship defined cancer survivorship as starting at the moment of diagnosis and continuing for the rest of a person's life. He observed that some cancer survivors were cancer free, whereas for others, there were late and long-term effects of cancer and/or its treatment.2 Subsequently, in the past 25 years, the Institute of Medicine and others have recognized cancer survivorship as a separate and distinct phase of cancer care. The "seasons of survival" remain essentially the same, though a distinct phase of transition after the completion of therapy has been recognized, along with the heterogeneity of cancer survivors who are in long-term, permanent survivorship.3

Appendicitis is cured surgically, and pneumonia is cured with antibiotics. In contrast, diabetes, hypertension, and HIV are managed, treated, or controlled. In cancer care, several terms are used for patients who are free of disease including, "in remission," "no evidence of disease," and "doing well." Sometimes the word cured is used, but it is difficult to find an accepted cancer-related definition of the word cure. Many oncologists describe large-cell lymphoma or testicular cancer as curable and treat patients with these cancers with curative intent, but are then hesitant to describe any individual patient as cured.

There are many reasons for this hesitancy. The possibility of a late recurrence is one concern. For breast cancer survivors, the risk of late recurrences continues for decades after treatment, as was reported more than thirty years ago. A retrospective study conducted in 1979 of 3,878 women with breast cancer reported relapses occurring even 40 years after treatment and concluded that "only patients who have undergone the menopause before presentation and who are disease-free 15 years after primary treatment may prove to be cured."4 Later, in 1995, a Finnish study of 563 women also reported many late relapses but noted that, after excluding women diagnosed with a contralateral breast cancer, no deaths were identified after the 27th year of follow-up evaluation. They concluded that breast cancer "may be permanently cured even if treated with locoregional therapy alone."5 More recently, in a 2009 review, the authors conclude that survival has improved in breast cancer but that, "the jury is still out as to whether cure occurs in breast cancer but with ever-prolonging survival it looks more and more likely."6(p1292)

To our knowledge, the significance of oncologist and patient perceptions of cancer cure has not been described in the medical literature. Potentially, patients who do not think that they are cured want to continue follow-up care, including x-ray and laboratory studies, with their clinicians for years or decades. Clinician-recommended follow-up plans for visits and testing may also reflect a perception that patients are never cured and that ongoing surveillance is needed.

The purpose of this pilot study was to survey a group of oncology clinicians regarding their use of the word cure in their practice, as well as their patients' use of the word. Three case scenarios were presented to survey participants, who were then asked whether the patient is cured and whether they needed continued yearly follow-up with an oncologist.

Methods

A waiver was received from the institutional review board of the Dana-Farber Cancer Institute (DFCI) to survey the medical staff regarding use of the word cure in cancer care. E-mail requests were sent to 180 DFCI medical and radiation oncology faculty members requesting their participation. A second request for participation was sent to the faculty again approximately 1 week later. Faculty who agreed to participate were directed to an on-line questionnaire (Survey Monkey) consisting of a seven-page, 19-question survey. Of the respondents, 21 completed only the demographic section and did not answer any of the content questions; these were excluded from the analysis.

The clinicians were asked a series of questions regarding how commonly their patients are cured, though no specific definition of the word cure was given to the participants. They were also asked how often they use the word cure, in what circumstances they would tell a patient that they are cured, about the timing of telling a patient that they are cured, and about their hesitancy about using the word cure. The participants were then asked about their patients' perceptions about the word cure and use of the word. Finally, three hypothetical clinical cases were presented to the clinicians regarding patients who completed treatment 20 years ago. They were asked whether the patient is cured and whether they need to continue yearly follow-up.

Unpaired t tests and cross-tabulations with corresponding Fisher's exact test P values were used to characterize the clinicians' use of the word cure according to gender, age, subspecialty, and years since completion of training. Multiple linear regression and logistic regression models were used to assess the independent relationships of demographic characteristics with answers to the survey questions.

Results

Of the 180 faculty members invited to participate in the survey, a total of 138 responded (76.6%). Among the respondents, 21 only answered the demographic section, and these were excluded; results for the 117 (65%) remaining respondents were analyzed.

Demographics

Half of the respondents were men. The age ranged from 22 to 70 years, with an average of 44.7 years. Eighty-five (72.7%) of the respondents were physicians, and 55 (64.7%) of those were male. Among the physicians, the average time since completion of their oncology training was 13.3 years (standard deviation, 10.8 years). Nineteen percent of respondents specialized in breast cancer, 18% specialized in hematologic cancers, and the remaining were classified as "other" oncology specialty.

Use of the Word Cure by Clinicians

A summary of answers regarding the use of the word cure in cancer care is presented in Table 1.

Of the patients you have treated in your subspecialty, what percent do you think are or will be cured? On average, respondents answered that 38.3% (range, 0%-90%; median, 32.5%) of

their patients are, or will be, cured. Five percent of respondents believed that none of their patients will ever be cured, and 40.7% thought that between 0% and 25% of their patients will ever be cured. Practitioners specializing in breast oncology felt that 63% of their patients are, or will be, cured, almost double the proportion expected to be cured among hematologic oncology subspecialists (25.6%) and other subspecialists (36.8%; P < .001). Respondents in the youngest (20-29 years old) and oldest (60-70 years) age categories reported that a significantly smaller proportion of their patients are, or will be, cured (24.1%, on average) compared with those in the other age groups (40.3%, on average; P = .027). No significant differences were observed by sex (P = .401). In a multivariate linear regression model assessing independent predictors of the percentage of patients who the providers believed are, or will be, cured, only breast oncology specialization was statistically significantly and positively associated with the outcome (an increase of 25.9% relative to other oncology specialists, P < .001). The percentage of patients who respondents believed are, or will be, cured did not vary significantly by the respondents age, sex, or profession.

Are you as a clinician hesitant to tell a patient that they are cured? Overall, more than 80% of respondents indicated that they would be hesitant to tell a patient that they are cured. Although 14 of 18 breast oncology subspecialists (78%) responded that more than half of their patients will be cured, 89% of these same breast cancer specialists reported being hesitant to tell a patient that they are cured. Differences in hesitancy across age groups and number of years since training were not statistically significant (P > .16).

How long after completing the initial phase of their treatment would you first feel comfortable telling a patient that they are cured? Although 26 respondents (22.2%) had no answer to this question, 22% of the remaining 91 participants said they would first feel comfortable telling a patient that they are cured only after 10 or more years, 41.8% would be comfortable after 6-10 years, and 36.3% would feel comfortable after 0-5 years. Responses did not differ significantly by age of the respondent (P = .335), number of years since completing their training (P = .403), or sex (P = .078).

In a multivariate logistic regression model of participants who would feel comfortable telling a patient they are cured \geq 10 years after completing the initial phase of treatment, only being a breast oncology specialist was statistically significantly associated with an increase in the percentage of patients who respondents believed are, or will be cured, compared with a reference category composed of all other subspecialists (odds ratio = 6.6, P = .022). Participant's age and sex were of borderline statistical significance in this model.

Clinicians Perceptions of Patients' Views

Table 1 also shows a summary of answers regarding respondents' perceptions of patients' views regarding the word cure in cancer care.

Table 1. Clinicians' Use and Perceptions of the Word "Cure" in Cancer Care, by Profession

| | Physician Nurse Practitioner | | | Physician's Assistant | | Total | | | |
|--|------------------------------|-------------|-------------|--------------------------|------------|-------|-----|------|------------|
| Questions | No. | % | No. | % | No. | % | No. | % | P * |
| | Use | of the word | d cure | | | | | | |
| Of the patients whom you have treated in your subspecialty what percentage do you think are or will be cured? | | | | | | | | | .449 |
| 0-25 | 31 | 37.8 | 10 | 52.6 | 5 | 41.7 | 46 | 40.7 | |
| 26-50 | 25 | 30.5 | 3 | 15.8 | 6 | 50.0 | 34 | 30.1 | |
| 51-75 | 20 | 24.4 | 4 | 21.1 | 1 | 8.3 | 25 | 22.1 | |
| 76-100 | 6 | 7.3 | 2 | 10.5 | 0 | 0.0 | 8 | 7.1 | |
| Are you as a clinician hesitant to tell a patient they are cured? | | | | | | | | | .138 |
| No | 19 | 22.9 | 2 | 10.5 | 0 | 0.0 | 21 | 18.6 | |
| Yes | 64 | 77.1 | 17 | 89.5 | 11 | 100.0 | 92 | 81.4 | |
| How long after completing the initial phase of their treatment would you first feel comfortable telling a patient that they are cured? | | | | | | | | | .485 |
| 0-5 years | 28 | 41.2 | 3 | 18.8 | 2 | 28.6 | 33 | 36.3 | |
| 6-10 years | 26 | 38.2 | 9 | 56.3 | 3 | 42.9 | 38 | 41.8 | |
| > 10 years | 14 | 20.6 | 4 | 25.0 | 2 | 28.6 | 20 | 22.0 | |
| Clinicians' perceptio | ns of patie | ent's views | regarding I | use of the w | ord "cure" | , | | | |
| What percentage of patients ask you if they are cured? | | | | | | | | | .249 |
| 0-25 | 45 | 56.3 | 6 | 33.3 | 7 | 63.6 | 58 | 53.2 | |
| 26-50 | 16 | 20.0 | 6 | 33.3 | 2 | 18.2 | 24 | 22.0 | |
| 51-75 | 7 | 8.8 | 4 | 22.2 | 2 | 18.2 | 13 | 11.9 | |
| 76-100 | 12 | 15.0 | 2 | 11.1 | 0 | 0.0 | 14 | 12.8 | |
| Are patients hesitant to say they are cured? | | | | | | | | | .174 |
| No | 31 | 44.9 | 4 | 30.8 | 1 | 12.5 | 36 | 40.0 | |
| Yes | 38 | 55.1 | 9 | 69.2 | 7 | 87.5 | 54 | 60.0 | |

^{*} Fisher's exact test.

What percentage of patients ask you if they are cured? Among the 109 respondents who answered the question, participants responded that, on average, 34.5% (range, 0%–100%; median, 25%) of their patients ask if they are cured. Participants' estimates did not differ significantly by profession (P=.249), subspecialty (P=.195), age (P=.833), years since completion of training (P=.618), or sex (P=.504). No predictors were statistically significant in a multivariate logistic regression model.

Are patients hesitant to say that they are cured? Sixty percent of respondents believe that their patients are hesitant to say that they are cured. Again, participants' answers did not differ significantly by subspecialty (P=.731), age (P=.516), years since completion of training (P=.822), or sex (P=.514). No predictors were statistically significant in a multivariate logistic regression model (P>.05).

Case Presentations

A summary of answers regarding the three case presentations is presented in Table 2.

Case 1. You are seeing a man who was treated for testicular cancer 20 years ago. This was a seminoma; he received chemotherapy and has had no evidence of disease since then.

The percentage of participants who responded that the patient in case 1 is cured was 83.9% (94 of 112); physicians were significantly more likely to conclude that the patient was cured (92.9%) compared with nurse practitioners (55.6%) and physician's assistants (60%; P < .001). Only two physicians responded that the patient is not cured. Despite the high proportion of respondents who believed the patient is cured, 35.2% indicated that he still needs yearly oncology follow-up visits.

Case 2. You are seeing a woman who was treated for large-cell lymphoma 20 years ago. She received CHOP chemotherapy and has had no evidence of disease since then.

The percentage of participants who responded that the patient in case 2 is cured was 75.9% (85 of 112); again, physicians were significantly more likely to conclude that the patient was cured (83.1%) compared with nurse practitioners (63.2%) and physician's assistants (40.0%; P=.005). Despite the high proportion of respondents who believed the patient is cured, 42.7% of them indicated that she still needs yearly oncology follow-up visits.

Case 3. You are seeing a woman who was treated for breast cancer 20 years ago when she was 47 years old. This was a stage

Table 2. Case Presentations: "Is This Patient Cured?"

| | Physician | | Nurse Practitioner | | Physician's Assistant | | Total | | |
|-------------------------------|-----------|------|-----------------------|------|--------------------------|------|-------|------|------------|
| Survivor Case | No. | % | No. | % | No. | % | No. | % | P * |
| 1: Testicular cancer | | | | | | | | | < .001 |
| Yes | 78 | 92.9 | 10 | 55.6 | 6 | 60.0 | 94 | 83.9 | |
| No | 1 | 1.2 | 0 | 0.0 | 1 | 10.0 | 2 | 1.8 | |
| I don't know | 2 | 2.4 | 5 | 27.8 | 2 | 20.0 | 9 | 8.0 | |
| As oncologists, we don't know | 3 | 3.6 | 3 | 16.7 | 1 | 10.0 | 7 | 6.3 | |
| 2: Large-cell lymphoma | | | | | | | | | .005 |
| Yes | 69 | 83.1 | 12 | 63.2 | 4 | 40.0 | 85 | 75.9 | |
| No | 0 | 0.0 | 0 | 0.0 | 1 | 10.0 | 1 | 0.9 | |
| I don't know | 7 | 8.4 | 5 | 26.3 | 3 | 30.0 | 15 | 13.4 | |
| As oncologists, we don't know | 7 | 8.4 | 2 | 10.5 | 2 | 20.0 | 11 | 9.8 | |
| 3: Breast cancer | | | | | | | | | .574 |
| Yes | 39 | 47.6 | 10 | 58.8 | 4 | 36.4 | 53 | 48.2 | |
| No | 4 | 4.9 | 1 | 5.9 | 1 | 9.1 | 6 | 5.5 | |
| I don't know | 11 | 13.4 | 3 | 17.6 | 3 | 27.3 | 17 | 15.5 | |
| As oncologists, we don't know | 28 | 34.1 | 3 | 17.6 | 3 | 27.3 | 34 | 30.9 | |

^{*} Fisher's exact test.

1, infiltrating, ductal cancer that was estrogen receptor positive. She received chemotherapy (four cycles of Adriamycin and Cytoxan) and then 5 years of tamoxifen and has had no evidence of disease since then.

The percentage of participants who responded that the patient in case 3 is cured was 48.2% (53 of 110), substantially lower than for the previous two cases. Six of the participants (5.6%) responded "No," she is not cured. There were no significant differences between the different groups of practitioners' assessments of case 3 (P = .574). More than half (55.7%) of respondents indicated that this patient still needs yearly oncology follow-up visits.

When asked after how many years in remission patients should be discharged from a cancer center and monitored by their primary physician, 31.7% said "Never," whereas 61.0% were able to specify a certain number of years post-treatment. Forty percent of the respondents answered that cancer patients should be discharged from cancer follow-up in 5-10 years.

Discussion

The intent of medical therapy may be curative, palliative, restorative, or sometimes each of these for the same patient. In treating cholecystitis or appendicitis, a surgeon would have curative intent and then, after treatment, indicate that their patient is cured. In other diseases, such as diabetes or hypertension, the intent of treatment is typically to manage or control disease, and the term cure would not be expected. In cancer care, however, there is often curative intent, yet the term cure is infrequently used, if it is used at all.

This was a pilot study of the attitudes of oncology clinicians at a major academic cancer center about the use of the word cure in cancer care. Seventy-five percent indicated that they were hesitant to use the word. Sixty-six percent indicated that they

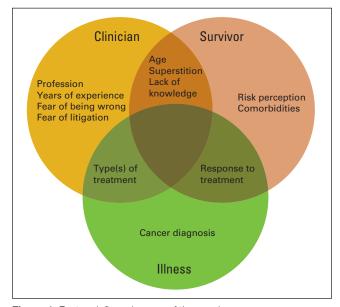


Figure 1. Factors influencing use of the word cure.

would use the term when the risk of recurrence was either under 5% or essentially zero, and 20% reported that they never use the word. When respondents were asked to evaluate two specific case studies of patients who were treated 20 years prior for seminoma or large cell lymphoma, close to 90% indicated that these patients were cured, but more than 30% felt that continued annual follow-up visits were needed. In a third case study, of a woman treated for breast cancer, the percentage of respondents who thought that she was cured was lower at 47%; 52% recommended yearly oncology follow-up care. Twenty-two percent of respondents would never discharge patients from cancer care.

Many respondents perceived that cancer survivors may be hesitant to be considered cured; 40% of clinicians indicated that their patients were hesitant to ask if they were or would be cured. Sixty percent of respondents indicated that less than half of their patients ask if they are, or will be, cured. Some cited their own and their patients' hesitancy as related to the continued risk of relapse. There was concern among some respondents that some patients would react with superstition about indications that they were cured (Figure 1).

The consequences of not using the word cure are unclear from this pilot study. Indicating that a patient is cured may imply a degree of confidence that exceeds the clinician's comfort level. In the literature, there have been instances of late recurrences of cancer, that is, more than 10 or 20 years after a patient had been perceived as cured. With anecdotal knowledge of patients who experienced late relapses, oncologists may not consider 5-year—and sometimes even 10-year—survival rates to adequately predict whether a specific patient is cured.^{7,8} Nonetheless, in the cases that were presented in this survey, close to 90% of clinicians indicated that certain patients were cured 20 years after treatment. It is unclear whether the clinicians would have told the patients in these case studies that they are cured. A large percentage of these clinicians recommended annual oncology follow-up care for these patients, though this survey did not attempt to elucidate the purpose of these visits. These data invite more research about the role and the purpose of follow-up visits throughout the cancer care continuum.

There may be substantial implications of not using the word cure. For cancer survivors, the uncertainty about being cured could be an ongoing source of worry. Being in remission, rather than cured, may emphasize the importance of surveillance for cancer recurrence and result in less focus on the other tasks of cancer survivorship care, including screening for late and long-term effects and second or secondary cancers, time and effort spent on secondary prevention, and treatment of comorbidities, all of which become more relevant with increasing age.

Using the word cured for cancer survivors may have positive outcomes, including facilitating positive psychosocial adapta-

tions and increased confidence. However, cancer survivors who are told that they are cured may discontinue or diminish their medical care. For clinicians, a determination that a patient is cured could justify their discharge from oncology follow-up and shift time and attention to newly diagnosed patients. For society, considering cancer a curable disease could promote cancer screening and early detection efforts.

This study is a single-institution pilot study using a sample of academic clinicians. Further research is needed to better understand the terminology choices and the underlying beliefs of clinicians and patients when using the words curable, curative intent, in remission, no evidence of disease, and cured. Similarly, it will be important to study the use and perceptions of the word cure among academic and community oncologists; medical, radiation, surgical, pediatric, and gynecologic oncologists; and primary care providers, cancer survivors, and their family and caregivers. The follow-up care recommended for cancer survivors is also an important field of research that has important implications for our health care system.

Authors' Disclosures of Potential Conflicts of Interest

The author(s) indicated no potential conflicts of interest.

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Conception and design: All authors

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